CHAPTER III.3. COST OF CLEFT LIP AND PALATE

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CHAPTER III.3. COST OF CLEFT LIP AND PALATE

III.3.A Background

This chapter contains a discussion of the methods used and the results of estimating the direct medical costs incurred by individuals with cleft lip and/or palate, and the results of the analysis.[1] It does not include information on elements such as indirect medical costs, pain and suffering, lost time of unpaid caregivers, etc. The reader is referred to Chapter I.1 for a discussion of the cost estimation methods and cost elements that are relevant to all benefits estimates. In addition, Chapter III.1 contains information regarding the special characteristics of developmental defects, and a list of chemicals that may cause developmental abnormalities.

The costs presented in this chapter were current in the year the chapter was written. They can be updated using inflation factors accessible by clicking on the sidebar at left.

Link to Chapters I.1 and III.1
Link to inflation factors

III.3.A.1 Description

Cleft lip and palate occur when structures in the nose and mouth fail to close during embryonic development. These birth defects appear as openings or incomplete structures in the centerline of the face and mouth. They often occur concurrently (approximately 50 percent of the time), due to the mechanism of damage that leads to these defects (Fraser, 1970). Cleft lip and palate may involve a small or large portion of the facial structures associated with the nose and mouth. Without treatment, infants may have problems sucking and swallowing and may aspirate food into their lungs. Other problems arising from this deformity include delayed and distorted speech, ear and sinus infections, reading disabilities, crossbite, and problems with social interactions (Waitzman et al. 1996).

The incidence of cleft lip and palate varies across ethnic groups. Cleft lip, with or without cleft palate occurs in approximately one in 1,000 births among whites, 0.3 in 1,000 among blacks, 3.5 in 1,000 among Native Americans, 1.7 in 1,000 among Chinese, and 2.5 in 1,000 among Japanese (Oski, 1994). Although there are over 300 recognized cleft syndromes, these represent a small percentage of the total cleft cases (Oski, 1994).

[1] "Costs" in this chapter refer to direct incremental per capita medical costs, unless otherwise noted.

III.3.A.2 Concurrent Effects

More than 50 percent of infants born with cleft lip and/or palate have other anomalies of the face, heart, and head (microcephaly). Cleft lip and/or palate occur with slightly greater probability in individuals with Down syndrome than in the general population (Waitzman et al. 1996). Middle ear infections are a common occurrence in children with cleft palate (Oski, 1994).

III.3.A.3 Causality

Cleft lip and palate occur early in development, when the basic skeletal structures are being formed. The latest time that this anomaly can be induced is approximately 36 days post-conception (Bennett and Plum, 1996). Consequently, factors that cause this disorder must occur before the pregnancy begins, or in its very early stages.

Both genetic and environmental factors may be responsible for cleft lip and palate, inhibiting the normal flow of cells during development. A long list of teratogenic substances can cause clefting in rodents, including corticosteroids, folic acid inhibitors, Vitamin A, and phenytoin (Oski, 1994).

Table III.1-1 in Chapter III.1 lists numerous chemicals associated with developmental abnormalities in human and/or animal studies. Many of these have identified structural and anatomical defects. Cleft lip and palate fall into this category of defects. Little human data exist on developmental effects of chemical exposures, as discussed in Chapter III.1, even though birth defects are relatively common occurrences.

Link to Table III.1-1 in Chapter III.1

Twin data suggest some genetic component to the occurrence of cleft lip and palate; however, only 35 percent concordance in the occurrence of the disorder is seen in identical twins. A simple genetic inheritance pattern is therefore not responsible for the disorder in most cases (Oski, 1994), or all identical twins (who have the same genetic composition) would have identical patterns of occurrence (i.e., either both or neither would have the anomalies).

A recently completed study of the offspring of pesticide application workers found that their incidence of skeletal anomalies (as well as respiratory system, circulatory system, and urogenital anomalies) were significantly greater than those of the general population in the same area of the United States (Garry et al., 1996). Musculoskeletal anomalies include any abnormality in the size, shape, or function of part of the skeletal system, muscles, and related tissues (e.g., cartilage). They include

the absence or shortening of limbs (as discussed in Chapter III.4) and the abnormal formation of part of the skeleton or related soft tissue and cartilage, as is the case in cleft lip and palate. The chemicals evaluated in the Garry et al. study that were associated with the birth defects were trifluralin, triazine herbicides (including atrazine, a very common well contaminant in agricultural areas), and chlorophenoxy herbicides (including MCPA and 2,4-D, a pesticide with very high usage). There was also a significant increase in birth defects among infants conceived in the spring (i.e., during peak chlorophenoxy use) compared to infants conceived during other periods of the year (Garry et al., 1996).

As indicated in Chapter III.1, the timing of exposure is often a critical determinant of whether and what type of effects will occur. Generally, the earlier during a pregnancy that damage occurs, the more serious the effect will be because all cells developing from the damaged cells may also be damaged, and basic structures are being formed during the first trimester (three months). Although Garry et al. do not provide detailed information on the specific nature of the anomalies, this information can be obtained from the authors of the study or from EPA (the work was funded by U.S. EPA).

Link to Chapter III.1

III.3.A.4 Treatment and Services

Cleft lip and palate are typically corrected during infancy or early childhood. They are usually treated surgically shortly after birth to close the lip. Surgical correction of the palate typically occurs at 6 to 18 months. Remaining defects are corrected during adolescence. Speech and orthodontic services are frequently required (Waitzman et al., 1996). A medical team consisting of a maxilofacial surgeon, audiologist, speech pathologist, prosthodontist, otolaryngologist, pediodontist, and geneticist are often involved in the treatment of this disorder over an extended period during childhood.

III.3.A.5 Prognosis

Long-term survival and quality of life after the first year of life are good, in the absence of other medical problems. As noted under concurrent effects above, other anomalies that frequently accompany cleft lip and palate may shorten life and diminish abilities (Waitzman et al., 1996). The mortality experience in California of individuals born with cleft lip and/or palate as reported by Waitzman et al. is discussed in Section III.3.B.

III.3.B Costs of Medical Treatment and Other Services

Cleft lip and palate are typically corrected during infancy or early childhood; consequently, their cost evaluation is simpler than many of the other developmental effects discussed in this handbook. Cleft lip and palate correction focuses on surgical and other medical care that occurs over a relatively short time period. The medical procedures often fully address the problem, and there are not medical costs occurring over the lifespan of the individual, as there often are with effects such as spina bifida and cerebral palsy (Waitzman et al., 1996).

As noted above, cleft lip and palate are very often associated with other birth defects. They also occur with slightly greater probability in individuals with Down syndrome than in the general population. Consequently, it may be necessary to evaluate the costs of multiple effects in addition to cleft lip and palate (Waitzman et al., 1996). The need for this type of analysis is supported by the occurrence of multiple birth defects in toxicological tests of environmental chemical exposures in animals. Multiple effects, which often occur from exposure to chemicals, would all be considered in a comprehensive cost estimate.

III.3.B.1 Methodology

This chapter and chapters III.4 through III.8 in this section use cost of illness estimates developed by primarily Waitzman et al. (1996). The methodology and relevant considerations are discussed in detail in the following sections. The results and elements related specifically to each condition are then discussed in each individual chapter.

To estimate the lifetime medical costs incurred by an individual with a birth defect, Waitzman et al. estimated the average lifetime medical costs for an individual with the birth defect. From this value, the authors subtracted the average lifetime medical costs for an individual without the birth defect. This method has two important implications. First, unlike the costs reported for many of the diseases in this handbook, cost estimates based on Waitzman et al. include the costs of concurrent effects. These estimates yield a more comprehensive assessment of total costs than would be obtained if only individual effects were evaluated. This is of particular use in valuing the avoidance of birth defects because they very frequently occur in clusters within an individual. Second, the Waitzman et al. method estimates the incremental costs for individuals with birth defects — that is, the costs above and beyond the average costs that would be incurred by individuals without the birth defect.

The Waitzman et al. cost estimates are well-researched and up-to-date. These cost estimates are based on ongoing costs of birth defects in California across many ages and the occurrence of birth defects in a large

cohort of children born in California in 1988. The state of California has spent considerable resources to evaluate causes and occurrences of birth defects and has an ongoing birth defects monitoring program. Consequently, the use of this state data provides excellent sources of information on occurrences, costs, and related information. California's large size and diversity makes it a good heterogenous source of cost data.

Waitzman et al. used multiple databases, including the California Birth Defects Monitoring Program incidence, birth, and death records, the National Health Interview survey, The California Office of Statewide Health Planning and Development hospital discharge data, MediCal claims files, California Department of Development Services data, the National Longitudinal Study of Special Education Students, California Special Education Enrollment and Expenditure data, and the Survey of Income and Program Participation. The variable-specific data sources and limitations will be discussed in greater detail in Section III.3.B.1.6.

III.3.B.1.1 Direct and Indirect Costs

Cost of illness studies typically involve analysis of two types of costs: direct and indirect. Direct costs are associated with resources *used* to provide medical care to people with a particular illness. These costs include medical costs such as inpatient and outpatient costs, and nonmedical costs, such as the cost of special education. Indirect costs, on the other hand, are associated with resources *lost* to society as a result of premature mortality and/or morbidity in patients. These costs are related to activity limitations and include foregone earnings.

Waitzman et al. (1996) estimated three categories of costs: direct medical costs, direct nonmedical costs, and indirect costs. Direct nonmedical and indirect costs are reported at the end of this chapter without discussion for the reader's convenience. Direct medical costs, specifically inpatient care, outpatient care, pharmaceuticals, laboratory tests, X-rays, appliances, and long-term care are included in the direct medical cost estimates shown in this chapter. For more information on methods used to derive these costs, the reader may wish to consult Waitzman et al. (1996).

III.3.B.1.2 Prevalence versus Incidence

Cost of illness studies usually employ either a prevalence or an incidence approach. The prevalence of an illness at a given point in time is the number of individuals who have the illness at that time. The prevalent population is defined as a cross section of the population with the disease of interest at a given time. This group may be subdivided into age-specific prevalent populations. Incidence refers to the newly diagnosed cases of an illness. The incidence of an illness in a given year, for example, is the number of cases of the illness that were newly diagnosed in that year.

Prevalence approaches are more useful for assessing treatment strategies. Incidence approaches, on the other hand, are more useful for assessing prevention strategies, because preventing the occurrence of an illness avoids the entire stream of costs that would have resulted from the illness from its inception to the death of the individual. Part of the benefit of preventing an illness is the benefit of avoiding the costs associated with the illness, measured as the present discounted value of the stream of costs that would be incurred over the entire course of the illness (Waitzman et al., 1996).

Waitzman et al. use an incidence-based approach, but use both incidence and prevalence numbers to arrive at the final incidence-based estimates. Cross-sectional cost data from the larger population group of all California residents diagnosed with a condition (i.e., the prevalent population) were divided by the total number of people in this group to obtain estimates of the costs for the cohort of interest (i.e., those born in 1988). These costs were adjusted based on the average cost for a healthy individual, in order to obtain incremental costs (discussed below). The per-capita incremental costs were then multiplied by estimates of the size of the 1988 cohort at each age (i.e., the incident population) to obtain a total incidence-based, age-specific cost estimate for the 1988 cohort. Finally, the total costs were divided by the size of the cohort at birth with each defect to obtain the cost per case.

Table III.3-1 provides California prevalence data for a point in time (July 1, 1988) and California incidence data for infants born in 1988 for cleft lip and palate, along with other commonly observed developmental defects. This table shows the differences between prevalence and incidence, as well as the variation across defects in each. Although no exact relationship between the prevalence of these conditions on July 1, 1988 and their incidence during 1988 exists, the two are highly correlated. For example, the two conditions with the highest incidences in 1988 (cleft lip or palate and cerebral palsy) are also the two most prevalent conditions on July 1, 1988. The third most prevalent condition on July 1, Down syndrome, also has the third greatest incidence during 1988. The least prevalent condition, truncus arteriosis, has the lowest incidence.

Table III.3-1: Prevalence and incidence of the most frequent birth defects in California: 1988*

Condition	Prevalence of the Birth Defect on July 1, 1988**	Incidence of the Birth Defect Among Infants Born in California in 1988***
Spina bifida (Ch. III.6)	8,859	226
Truncus arteriosis (Ch. III.5)	1,591	56
Transposition (Ch. III.5)	7,469	263
Tetralogy of fallot (Ch. III.5)	5,336	187
Single ventricle (Ch. III.5)	1,932	68
Cleft lip or palate	24,956	944
Upper limb reduction (Ch. III.4)	7,895	234
Lower limb reduction (Ch. III.4)	3,856	114
Down syndrome (Ch. III.8)	14,095	558
Cerebral palsy (Ch. III.7)	28,745	656

* Numbers are from Tables 3-1 and 3-4 in Waitzman et al., 1996.

**The prevalence of a birth defect at a given time is the number of individuals (of all ages) who have the birth defect at that time.

***The incidence of a birth defect in a given year is the number of infants born with the birth defect during that year. For example, whereas there were 8,859 individuals (of all ages) in California on July 1, 1988 who had spina bifida, 226 babies were born with spina bifida in California during 1988. Those infants born with spina bifida in California in 1988 on or before July 1 and still alive on July 1 would be counted among the prevalent population on July 1, 1988.

Waitzman et al. estimated the lifetime costs of birth defects in a cohort and therefore used an incidence-based approach. Ideally, they would have tracked the costs of the cohort members over time, until the death of the last cohort member. Because the members of the cohort were born in 1988, however, this was not possible. Instead, estimates of the costs incurred at each age were based on estimates of per capita costs in the prevalent population of that age. The method is described more fully in Section III.3.B.1.5.

III.3.B.1.3 Incremental Costs

Waitzman et al. emphasize that their cost estimates are "cost estimates for individuals with birth defects rather than the costs of the birth defects per se" (Waitzman et al., 1996). They are, moreover, estimates of *incremental*

costs. Because medical costs are incurred by the population as a whole, the costs incurred by an individual with a birth defect must be adjusted to reflect these baseline costs. The per capita *incremental* cost of a birth defect is the cost incurred above and beyond the cost incurred by an "average child" without the birth defect. Waitzman et al. attempted to isolate those costs specifically related to the condition of interest and associated anomalies. In order to do this, the costs for each individual with a particular effect (e.g., cleft lip) were tracked. Costs for the average non-affected person were subtracted from those for the average person with the effect.

III.3.B.1.4 Costs of Concurrent Effects

Many of the defects discussed in the following chapters are associated with other defects. By their nature, Waitzman et al.'s cost estimates include the costs of concurrent effects. As noted above, Waitzman et al. estimated the costs incurred by individuals with birth defects, including all medical costs incurred, rather than the cost of the birth defect per se. For example, the mean per-capita cost incurred by a person with Down Syndrome would include the costs associated with other defects. This approach has advantages and disadvantages (as discussed in detail by Waitzman et al.). If two defects are dependent, then it makes sense to include costs related to both conditions; the benefits of preventing the first would be equal to the costs of both, since prevention of one leads to prevention of the other. Alternatively, if two defects are independent of each other but show up in the same person, this methodology would yield an overestimate of costs.[2] Little is known about the pathogenesis of birth defects, and the assumption is that most defects fall somewhere in between total dependence and independence. Given the relative rarity of many severe birth defects, the probability that they would occur in the same person, without any linkage in causation, is very small.

As Waitzman et al. note, the costs of associated anomalies are included as part of the estimate of the costs incurred by an individual with a given birth defect. For this reason, their cost estimates cannot be aggregated across birth defects because of the possibility of double counting.

Given the large size of the California databases used by Waitzman et al., the combination and frequency of concurrent effects in the authors' sample are likely to be representative of those in the larger United States population, and therefore appropriate for a benefits assessment.

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[2] Waitzman et al. address this situation when they extrapolate the per-capita mean costs to the total mean costs per disease. Rather than including a single person in the incidence totals for both Down syndrome and cleft palate, for instance, they include a person with both defects in the incidence total of the more costly defect. When the per-capita costs are multiplied by the total number of people with the defect, each person is counted only once. The costs in this handbook focus on the per-capita costs only. Consequently, the adjustment described above is not applicable to the costs presented here.

III.3.B.1.5 Analysis

The estimation of the average per capita lifetime cost associated with a birth defect is based on the method of Waitzman et al. (1996). Waitzman et al. estimate both the total lifetime cost for a *cohort* of individuals and the average lifetime cost per case — i.e., for a single individual in the cohort. (The average cost per case is obtained by simply dividing the total cost for the cohort by the original number of individuals in the cohort.) The Waitzman et al. method is discussed briefly below.

Waitzman et al. estimate the present discounted value of lifetime costs associated with a birth defect for a cohort born with the defect in 1988 in California. This value is the sum of costs over all years in which cohort members are alive, with future costs discounted appropriately. The total costs incurred during the first year after birth, denoted TC_1, are the costs incurred by all members of the cohort who survive to one year of age; these costs are discounted back to the year of birth by dividing TC_1 by the discount factor for the first year, $(1 + r)$, where r is the discount rate. The total costs incurred during the second year after birth, denoted TC_2, are the costs incurred by all members of the cohort who survive to two years of age; these costs are discounted back to the year of birth by dividing TC_2 by the discount factor for the second year, $(1 + r)^2$. In general, the costs incurred during the *i*th year after birth, TC_i, are the costs incurred by those members of the cohort who survive to age *i*. These costs are discounted by dividing by the discount factor for the *i*th year, $(1 + r)^i$.

The total cost of the birth defect, COBD, is the sum of these discounted age-specific total costs:

$$COBD = \sum_i TC_i/(1+r)^i .$$

As discussed in Section III.3.B.1.3, the total costs incurred at a given age are *incremental* costs — that is, those costs above and beyond the costs incurred by the average child of that age.

Link to Section III.3.B.1.3

One way to estimate TC_i, the total incremental costs during the *i*th year after birth (i.e., at age *i*), might be to estimate the incremental costs incurred by those members of the cohort who survive to age *i*. For a cohort born in 1988, however, this calculation would be possible only through age nine, because members of that cohort would reach that age in the present year, 1997. Waitzman et al. instead base their estimates of total incremental costs for a given age on costs in the *prevalent* population of that age. For example, the average per capita total incremental cost among 15-year-olds is estimated from data on individuals with the birth defect who are 15 years old (none of whom can be members of a cohort born in

1988). This method assumes that the real costs associated with the birth defect for individuals of a given age will not change appreciably over time — for example, that the real costs for a 15-year-old in the year 2003, when the surviving members of the cohort born in 1988 are 15, will be the same as the real costs for an individual who is 15 years old in the prevalent population examined (e.g., in 1988). Waitzman et al. note that this conclusion in turn rests on the assumption that future treatment patterns will resemble current treatment patterns. An estimate of the per capita cost based on the prevalent population of age *i*, $PCPREV_i$, multiplied by an estimate of the number of individuals in the 1988 cohort who are expected to survive to age *i*, S_i, yields an estimate of the total incremental costs of those cohort members who survive to age *i*:

$$TC_i = (S_i) \times (PCPREV_i) .$$

Waitzman et al. estimate per capita costs in the prevalent population of age *i*, $PCPREV_i$, in two different ways, depending on data availability. One method is to simply divide the total costs in the prevalent population of age *i* by the number of individuals in that population. If the necessary information is not available for this method, an alternative method is used. Not all individuals with birth defects incur incremental costs at each age. The alternative method estimates the proportion of the prevalent population at age *i* who do incur incremental costs, and multiplies that proportion by the average per capita costs incurred by the individuals who incur costs. This second method is used when estimates of the total or per capita costs for the prevalent population of age *i* are not available, but estimates of the average per capita cost for those incurring costs are available.

The focus in this handbook is on the expected lifetime incremental costs for an individual with the birth defect — i.e., the average lifetime cost per case. As noted above, Waitzman et al. obtain this value by simply dividing the total cost for the cohort by the original number of individuals in the cohort. This method is equivalent to following the calculation outlined above, with one alteration: now, the *probability* of surviving to age *i* among those individuals born with the birth defect, ps_i, is used, rather than S_i, the *number* surviving to age *i*.[3] The expected per capita cost at age *i*, PCC_i, of an individual born with the birth defect would then be:

$$PCC_i = (ps_i) \times (PCPREV_i) .$$

[3] To estimate the number of cohort members surviving to a given age, Waitzman et al. multiplied the number in the original cohort by an estimate of the probability of surviving to that age. The data necessary to estimate survival numbers therefore include the data necessary to estimate survival probabilities.

The present discounted value of expected per capita lifetime costs of the birth defect, PCCOBD, is just the sum of these expected age-specific per capita costs, appropriately discounted:

$$PCCOBD = \sum_i PCC_i/(1+r)^i .$$

III.3.B.1.6 Variable-Specific Data Sources

Table III.3.2 lists the data sources used for each variable necessary for the calculations described above. It also briefly describes the limitations associated with each of these sources, and the methodology used to derive the data from the relevant sources.

Table III.3-2: Variable specific data sources and limitations

Variable			Source	Data Limitations
Number surviving to a given age, S = I×m	I (Incident Cases) (not including Cerebral Palsy)		CBDMP [1]	1. Actual numbers were not collected for three major counties, but were estimated for the study. These estimates could be biased. 2. Only live-born children are included. 3. Certain internal defects are not apparent during the first year, and therefore prevalence may be underestimated. 4. Does not account for birth defects treated exclusively on an outpatient basis.
	I (Cerebral Palsy)		CA Cerebral Palsy Project	1. Exceptionally stringent criteria for including cases. May underestimate.
	m (age-specific survival proportion)	Age 0-1	CBDMP linked with death certificates	1. Assumes that mortality at time of database is same at time of study — overestimates costs. 2. Assumes normal mortality beyond a specific age — underestimates costs.
		Quadrant IV conditions	MEDLINE search for each condition	
		Mortality	Review of clinical lit, panel of clinical advisors	1. Assumption of normal mortality beyond a specific age — may overestimate the number of survivors.

Table III.3-2: Variable specific data sources and limitations			
Variable		**Source**	**Data Limitations**
Size of the prevalent population	Age 0-1	CBDMP and incidence estimate (see above)	1. Applied 1983-86 estimates to 1988 — assumes that these numbers are similar. 2. Underestimates # of children who actually used services, i.e, if a child died before the one year cut-off date they would not be included, and yet they may have received care. 3. Assumed first-year mortality was equal among males and females. 4. Net migration not accounted for — may underestimate prevalence if families migrate to CA b/c of the availability of specialized care.
	After age 1	NHIS [2]	1. Assumes no net migration and no mortality over time. These two may actually cancel each other out. 2. Assumes that the prevalence of each defect has been constant over time.
Total incremental costs in the prevalent population (for each age)	Inpatient/Outpatient	OSHPD [3] (adjusted using MediCal and cost-to-charge ratios)	1. Cost-to-charge ratio may be too drastic.
	Long-term (Down syndrome and cerebral palsy)	DDS file [4]	
	Long-term (others)	MediCal	1. Assumed that all costs were borne by Medical. 2. Assumed that expenditures for such care were at cost.
	Other	Shriners' hospitals (add'l data not reported in OSHPD or MediCal)	
	Incremental Costs	NMCES [5]	1. These data may include persons with defects and therefore might be slightly overestimated, making incremental costs slightly underestimated.
PCAFF	Developmental Costs	DDS file	1. Unlikely that all underlying etiologies were recorded — may have underestimated # of people w/ birth defects receiving DDS services.
TC — special education	fc — proportion of the affected population	SRI [6]	1. Assumed the national distribution applied to CA.
	p — proportion receiving special ed	NHIS	1. May underestimate proportion receiving special ed.
	PCFC — per-capita special education costs	CA State Department of Education	
	CALPROP-the distribution of students	CA Department of Education	

[1] California Birth Defects Monitoring Program
[2] National Health Interview Survey
[3] 1988 California Office of Statewide Health Planning and Development hospital discharge file
[4] California Department of Developmental Services Masterfile, 1988-89
[5] National Medical Care Expenditure Survey, 1987
[6] National Longitudinal Transition Study of Special Education Students, 1990

III.3.B.2 Results

III.3.B.2.1 Annual Direct Medical Costs

Waitzman et al.'s (1996) estimates of the total lifetime medical costs of cleft lip and palate are outlined in the following tables. They are updated from 1988 to 1996 dollars based on the medical care cost component of the Consumer Price Index (1996:1988=1.6465). Table III.3-3 shows annual per capita medical costs incurred by individuals with cleft lip and palate by age group.

Table III.3-3: Annual Per-Capita Medical Costs of Cleft Lip and Palate by Age Group (1996$)

Condition	Age 0-1	Age 2-4	Age 5-17	Age 18+
Cleft lip and palate	$11,186	$2,025	$1,510	$1,421

III.3.B.2.2 Incremental Lifetime Direct Medical Costs

The medical cost of the average population was then subtracted from these costs to obtain incremental costs. Waitzman et al. (1996) discounted these costs using three different discount rates: two percent, five percent and ten percent. Although these discount rates do not match the standard EPA rates used in many other chapters in this handbook (zero percent, three percent, five percent and seven percent), there is insufficient information provided in Waitzman et al. (1996) to allow a conversion to discounted costs using standard EPA discount rates. This problem exists in all chapters based on the Waitzman et al. data (Chapters III.3 through III.8). The present discounted values of average per capita lifetime incremental costs, using discount rates of two percent, five percent, and seven percent, are listed in Table III.3-4 below.

Table III.3-4: Per-Capita Incremental Medical Costs, Nonmedical Costs, and Total Costs of Cleft Lip and Palate (1996$)

Cost Element	0%	2%	5%	10%
Direct Medical Costs		$19,758	$18,111	$16,465
Direct Non-Medical Costs:				
Developmental Services		$688	$649	$589
Special Education		$5,218	$3,866	$2,453
Total Direct Costs		$25,664	$22,626	$19,507

The costs presented in this chapter were current in the year the chapter was written. They can be updated using inflation factors accessible by clicking below.

Link to inflation factors

III.3.B.2.3 Other Costs

Categories of costs that are not usually included in this handbook were available from Waitzman et al. and so are reported in Table III.3-4. For information on their estimation methods see Waitzman et al. (1996).

III.3.B.2.4 Limitations

Reliance on the Waitzman et al. (1996) study has a number of limitations. The first concerns the reliance solely on California data. Medical practices and costs vary across the country, and an ideal data set would contain cost information from a representative sample of the entire United States. As a large state with varied areas (urban, rural, suburban, high, moderate, and low income populations), California is likely to reflect some of the diversity seen throughout the country. The California data are also especially accurate because of the birth defects monitoring program that the state has in place.

Another limitation involves the basis of the Waitzman et al. cost estimates. Waitzman et al. base their estimates of costs on *actual* costs incurred. To the extent that services were not readily available to or obtained by parents of children with birth defects in their sample, the Waitzman et al. estimates may understate the costs necessary for children to receive the level of care considered by doctors to be adequate.

What is considered "adequate" may, of course, vary from one individual to another (just as the willingness to pay to avoid the occurrence of a birth defect may vary from one individual to another). An alternative approach would be to delineate the collection of medical services and treatments that constitute "proper care" for a given birth defect or illness, as defined by consensus among doctors, and estimate the costs associated with that "bundle" of services and treatments. This theoretical cost methodology has the advantage of avoiding the possibility that the cost estimates may reflect the unwillingness or inability of parents to pay for adequate medical care rather than the cost of the care itself. These "ideal" costs are the costs of the care that, according to doctors, *should* be received. They are thus likely to be closer to the benefits to society of avoiding an illness. Actual costs, on the other hand, reflect the care that actually *is* received, and are therefore presumably a more accurate representation of what occurs.

The degree to which actual costs understate "ideal" costs will depend on the illness. Children with a life-threatening heart anomaly (See Chapter III.5) will typically be diagnosed properly at birth and require treatment, whereas children with Down syndrome may receive varying degrees of services to address their needs, depending on parental and other social factors and economic resources.

Waitzman et al. point out other limitations of their study, several of which are likely to lead to underestimates of cost. For example, they underestimate developmental services costs because the Department of Developmental Services file included only public expenditures, not private, out-of-pocket spending. In addition, the databases do not necessarily include complete longitudinal profiles of costs for all individuals because it was not always possible to link an individual's files across the entire lifespan. This omission would also result in underestimates of total lifetime costs. Finally, costs could be either under- or overestimated due to changes in technologies. Because the study attempts to estimate lifetime costs, changes in medical care technologies or policies could be important. These changes could either increase or decrease costs.

A final limitation warrants mention. Only select costs are presented in this chapter. There are other important categories of costs that are not included here. For example, a person born with a birth defect often has a higher probability of early death (see Section III.3.A.5, above); the cost of premature mortality is a real cost associated with many birth defects and illnesses. Individuals with illnesses or birth defects often experience a decrease in productivity, resulting in a loss to society of goods and services. In addition, there are the indirect costs of the pain and suffering of the individual and of family members, as well as the lost productivity of family members. These costs can be considerable (e.g., the direct cost of lost work time calculated for spina bifida by Waitzman et al. was $656,879 in 1996 dollars). These costs, while not presented for most illnesses in this handbook, are valid components of the total economic costs associated with the illnesses and birth defects discussed in this handbook.

Link to Section III.3.A.5